

FINDING OVARIAN CANCER EARLY IN HIGH-RISK WOMEN



A Cancer Genetics Network (CGN) Study

In collaboration with Ovarian Specialized
Programs of Research
Excellence (SPOREs)

Sponsored by NATIONAL CANCER INSTITUTE
National Institutes of Health

The CGN & SPORE Programs

The Cancer Genetics Network (CGN) is a network of cancer researchers from universities and hospitals nationwide. These centers are working together to learn more about cancer and genetics, including research on finding cancer early in high-risk women. The Ovarian Specialized Programs of Research Excellence (SPOREs) focus on moving discoveries made about ovarian cancer in the laboratory to the doctor's office. Both CGN and SPORE programs are sponsored by the National Cancer Institute.

Other medical centers also are participating.

For more information, call your nearest center.

CGN Centers

- **Lombardi Cancer Center CGN**
Washington, D.C.
Georgetown University
202-687-9490
- **Mid-Atlantic CGN**
Maryland
John Hopkins University, Baltimore
1-877-880-6188 or 410-502-7660
- **Carolina-Georgia Center of the CGN**
North Carolina
Duke University, Durham
1-866-292-7546

University of North Carolina,
Chapel Hill
1-877-692-6960

Georgia
Emory University, Atlanta
404-727-3799

- **Northwest CGN**
Washington
Fred Hutchinson Cancer Research Center,
Seattle
1-800-616-8347
- **Rocky Mountain Cancer Genetics Coalition**
Colorado
University of Colorado, Aurora
1-877-700-0697, ext. 2

Utah
Huntsman Cancer Institute, University of
Utah, Salt Lake City
1-877-585-0473
- **Texas Cancer Genetics Consortium**
Texas
MD Anderson Cancer Center, Houston
**1-800-392-1611, ask for Gynecology
Department**

Baylor College of Medicine, Houston
713- 798-1986

University of Texas, San Antonio
210-567-4274

University of Texas Southwestern Medical
Center, Dallas
1-800-688-5597, ext. 4
- **UCI-UCSD CGN**
California
University of California, Irvine
1-866-542-9875
- **University of Pennsylvania CGN**
Pennsylvania
University of Pennsylvania, Philadelphia
1-888-666-6002

Ovarian SPORE Centers

Alabama
University of Alabama, Birmingham
1-866-283-7223

Pennsylvania
Fox Chase Cancer Center, Philadelphia
1-800-325-4145

Other Participating Centers

Massachusetts
Dana-Farber Cancer Institute, Boston
1-800-828-6622, ext. 5

Massachusetts General Hospital
617-724-1971

Pennsylvania
Magee-Womens Hospital
University of Pittsburgh Health System
412-641-2501

Web sites:

CGN: <http://epi.grants.cancer.gov/CGN>

SPOREs: <http://spores.nci.nih.gov>

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About This Booklet

This booklet tells you about a new study looking at ways to find ovarian cancer (cancer of the ovaries) early in women at high risk for this kind of cancer. "High risk" means that you have more chance of getting ovarian cancer than other women. Women have a better chance of surviving ovarian cancer when it is found early. The study is called the "Risk of Ovarian Cancer Algorithm" study, or the ROCA study. We invite you to join this study.

Tell Me More About The Study

Ovarian cancer is often found late, when it is hard to treat. Doctors want to find ovarian cancer earlier, when it is easier to treat. This study looks at two tests, a blood test and an ultrasound exam.

The blood test checks for levels of a chemical in your body called CA125. Doctors have found checking CA125 levels helpful in finding a return of cancer in women who have had ovarian cancer in the past. However, it is unclear how CA125 can be used to find ovarian cancer in women who are not known to have it.

The ultrasound test uses sound waves to take pictures of your ovaries. These pictures can often tell doctors if there are problems in your ovaries. This study will help to see whether or not CA125 and ultrasound are useful in finding new ovarian cancer early.

Who Can Join?

You may join the study if you are age 30 or older, have not had ovarian cancer, and are at high risk.

High risk for ovarian cancer means that:

- you have a family history of 2 or more close blood relatives (mother, sister, daughter, grandmother) with breast or ovarian cancers,

OR

- you have a family history of 1 or more close blood relatives with breast or ovarian cancer and you are of Ashkenazi Jewish descent,

OR

- you or a close blood relative (mother, father, sister, brother, daughter, son, aunt, uncle, grandmother or grandfather) has tested positive for the BRCA1 or BRCA2 gene mutation (change). Testing positive for this gene change means that a woman has more chance of getting breast cancer than someone who has not had these gene changes.

What Will I be Asked to Do?

You will be asked to do the following if you join the study:

1. **Fill out forms.** At the first visit you will fill out a form about your health and your family's medical history. At following visits, you will fill out a shorter form about any changes in your health or your family's health related to cancer.
2. **Give a blood sample.** Every three months you will go to a medical center and have a small amount of blood taken from your arm. Doctors will look at the amount of CA125 in your blood. In addition, some women may be asked to get an ultrasound exam.
3. **Continue your regular medical care.** Continue to get your regular medical care.

How May I Benefit?

Here are some benefits you may get from being a part of this study:

- Your health will be watched closely by study staff.

- If you do get ovarian cancer, the study may help find it early. However, there is no guarantee that the study will find ovarian cancer early.
- You may help other women in the future by being part of a study looking at better ways to find ovarian cancer early.

Are There Any Dangers to Me?

- You may have some mild pain when they draw your blood.
- You may feel nervous waiting for your test results.

Is All My Study Information Kept Private?

Yes. All your information obtained for the study will be kept private. Every effort will be made to protect your confidentiality.

Can I Quit the Study After I Join?

Yes. Choosing to be a part of this study is your decision. You can also decide to leave the study at any time. This will not affect your medical care in any way.

How Can I Join or Learn More?

You can join the study by calling the project manager at the medical center nearest you. The medical centers taking part in the study are listed on the back of this booklet. Please call if you have any questions or want to learn more about the study.